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## A New Long-Term Care Manifesto

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This article argues for a fresh look at how we provide long-term care (LTC) for older persons. Essentially, LTC offers a compensatory service that responds to frailty. Policy debate around LTC centers on costs, but we are paying for something we really don't want. Building societal enthusiasm (or even support) for LTC will require re-inventing and re-branding. LTC has three basic components: personal care, housing, and health care (primarily chronic disease management). They can be delivered in a variety of settings. It is rare to find all three done well simultaneously. Personal care (PC) needs to be both competent and compassionate. Housing must provide at least minimal amenities and foster autonomy; when travel time for PC raises costs dramatically, some form of clustered housing may be needed. Health care must be proactive, aimed at preventing exacerbations of chronic disease and resultant hospitalizations. Enhancing preferences means allowing taking informed risks. Payment incentives should reward both quality of care and quality of life, but positive outcomes must be defined as slowing decline. Paying for services but not for housing under Medicaid would automatically level the playing field between nursing homes (NH) and community-based services. Regulations should achieve greater parity between NH and community care and include both positive and negative feedback. Providing post-acute care should be separate from LTC. Using the tripartite LTC framework, we can create innovative flexible approaches to providing needed services for frail older persons in formats that are both desirable and affordable. Such care will be more socially desirable and hence worth paying for.

**Key words:** Nursing homes, Autonomy, Choice, Consumer direction, Housing, Personal care, Chronic care

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The upcoming White House Conference on Aging prompts us to confront the challenge of long-term care (LTC) in an aging society. We cannot simply do more of the same. Rather, we should envision ways to deliver affordable LTC that allows recipients a livable life. Creating public support for meaningfully improving LTC will require a new public discourse, one based on a positive model for LTC, one that people see as worth supporting. This article offers some admittedly strong suggestions about why and how we might reconceptualize LTC.

Let's start by acknowledging a few basic truths. The LTC system is not what anyone would have designed. It has grown in fits and starts with one eye on efforts toward improving clients' function and the other on market opportunities, all done in the context of heavy regulation. The resulting system (certainly the predominant publicly funded system) has been shaped by payment policies and regulations; the latter have generally emerged in response to scandals or concern about quality; they emphasize technical care that reflects strong concerns about safety. We worry a lot about how to control the public costs of LTC; the major debates and planning efforts have centered on better ways to pay for LTC (e.g., the Pepper Commission and the CLASS [Community Living Assistance Services and Supports] Act (The Pepper Commission, 1990). One (often underappreciated) way costs are already held in check is through informal care, which has always been the backbone of LTC. Informal caregivers are the unsung heroes of LTC. The cost burden they eliminate should be acknowledged more. Moreover, informal care often presents a serious financial burden to families (Arno, Levine, & Memmott, 1999; Fast, Williamson, & Keating, 1999; Konetzka, 2014; Van Houtven et al., 2013). Without a lot of informal care, we're in big trouble.

The demographic forecasts remind us that we cannot afford to continue along our present course. We cannot serve substantially more people with a smaller labor force that provides both care and public money. But the elephant in the room is the fact that we are already paying a lot of money for care few people really want. Even those who can buy care privately have great difficulty finding the care they want (Kane & West, 2005). Indeed, we are foisting on our parents care we would not want for ourselves. We continue to patch the roof on a house that is structurally compromised and woefully out of date.

The LTC situation has become more confused because nursing homes (NHs), which are major providers of LTC, have seized a well reimbursed opportunity to expand their book of business into post-acute care (PAC). The post-acute care market created by the change in hospital payment under the imposition of DRGs enticed them into the more lucrative world of Medicare. Now institutions, many of which did not do a stellar job of LTC, were trying to provide a different level of care for which they were even less well prepared (Kane et al., 1998; Kramer et al., 1997;

Medicare Payment Advisory Commission, 2014). Likewise, home care (an LTC service) is conflated with home health care (a post-acute care service), and this confusion has become greater as the rules about Medicare coverage for home health care have changed. Discussions and analyses about LTC often fail to distinguish LTC from PAC.

The basic components of LTC are straight forward. They require an effective merger of housing (room and board), personal care, and medical care (largely chronic disease management). Figure 1 shows this conceptually. Each care recipient can be defined by a unique cell inside this matrix. Once the implied service needs have been identified a package should be tailored to an individual's needs and wants. A key precept is that many different service packages can be assembled to meet a given profile of needs. Cost and financial means cannot be ignored but should be treated as modifying factors rather than central engines. Some elements (like personal care services, for at least core services) might be thought of as universal entitlements, while other components may be more varied by ability to pay. A person could get the same level of personal assistance in living situations that vary in their level of amenities. In some instances, efficiency may require relocation. For example, someone who needs personal care several times a day may need to live in a more congregate setting because travel costs for caregivers are prohibitive; however, this need not mean sharing room with a stranger. Dwellings like apartments are conducive to sharing service resources without incurring extensive staff travel time. They still allow clients to preserve their autonomy and control their living situation.

### Where Do We Aim?

"When you come to a fork in the road, take it." (Yogi Berra). Although LTC has faced a series of crises, the current demographic and economic realities suggest a need for active reconceptualization. We face a major fork in the road. We can try to create the ideal system, but it may not

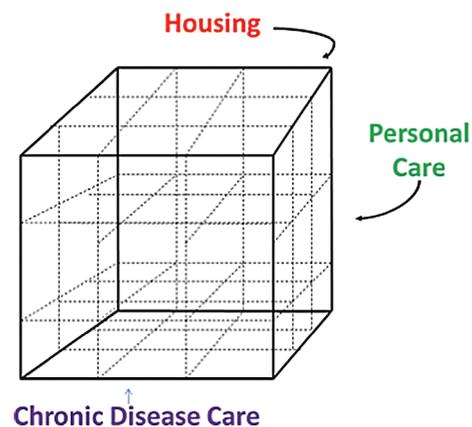


Figure 1. A conceptual model of long-term care.

be affordable; or we can look for a new approach that is both desirable and affordable. A prevalent business theory, disruptive innovation, offers a concept for changing LTC. Basically, this direction suggests that cheaper, more convenient products may drive existing ones out of the market, even if the new products are of lower quality (Christensen, 1997). In the context of LTC, continuing to use large institutions to deliver care no longer makes sense. We need to reconceptualize how we deliver this care. Demography suggests that not only are the numbers of older people growing, there are fewer workers to care for them. We may be able to use information technology, and even robotics, to redefine the way we provide LTC in the future. We might redefine how we use professionals, relying more on information support systems to more closely inform and monitor care delivered by lesser trained personnel.

We can look for compromises that would make LTC more affordable. No matter what, public funding will be needed. The real question is how much. The first big issue is how to maintain the crucial role of informal caregiving. That work absorbs a huge amount of the financial burden. The second step is to decide what triggers public involvement. The Pepper Commission talked about front- and back-end loading for payments (The Pepper Commission, 1990). The former involves giving everyone who needs care initial coverage and then stopping at a certain level of expenditure; presumably those in dire straits would continue to be publicly supported. The latter approach requires that people be expected to cover the initial costs of LTC up to some designated point; then public support would kick in. The trigger point could be linked to income. The poor would be covered from the outset. Most experts opt for back-ended coverage. This policy strategy is being pursued in the United Kingdom.

The strategic question is how to get people to save enough to pay that first part. Consumers may view saving or buying insurance for a modest amount of LTC as more feasible than trying to support all of it. For many, even this limited coverage may be enough. That sort of coverage is readily insurable because it is bounded. It may be possible to create an affordable insurance product to address the finite gap between the onset of care and when a government program would kick in.

The bigger challenge is creating a care system that has value. Must good care cost more? Can we re-examine the morass we have inadvertently created to find ways to deliver something different but more effective? We start by going back to the basic building blocks noted above and asking whether we need all the baggage we have mandated. We need to re-examine some of our basic precepts.

The first places to look are our insistence on more training and our reluctance to allow frail older people the right to take informed risks. We have striven to create a

system built around a goal of professionalism in response to frailty. Perhaps the fundamental touch points should borrow more from the disability world, and pursue goals around dignity, compassion, and autonomy. I am not arguing that skills and knowledge are not needed, but we can be more creative in how we apply them. Daily observations show that people can get by, perhaps even thrive, with less care than professionals are inclined to proffer. New communication technologies facilitate long-distance oversight of health workers. Right now one can employ some variation of a smart phone to monitor the work of a home care aide, including location and time spent with a given client. The same technology can be used to direct care, prompting areas to be observed, suggesting care to be given and receiving feedback about changes in client status. Linked to a system of proactive primary care, this technology supports a new way to manage chronic disease. Instead of a wasteful set of scheduled appointments, one would monitor the status of selected markers and intervene when the change in their condition suggested a deterioration. Some of the money saved by eliminating unproductive office visits could be used to support LTC.

Redesigning the system means letting go of some highly valued territory, especially regulations. The periodic exposés of bad care re-enforce the belief that even more stringent regulations are needed to protect vulnerable elders. But regulations, by their nature, constrain innovation at the very time we need to innovate. Critiques of regulation repeatedly note that they may help eliminate the very worst care, but possibly at the expense of improving care overall. Most regulation is dominated by those being regulated, and enforcement means lengthy legal battles. We want a policy that rewards more than it punishes. The idea of outcomes-based regulation is not new (Kane, 1976).

## A Proposal

Everyone wants to age with dignity and choice. Society is more likely to invest in care that has a positive social valence than one that simply provides necessary supportive care for people in need. The public dialog around LTC has to shift away from reliance on a sense of obligation to provide a socially necessary, but unattractive service, to one that offers something desirable. The goal for LTC is to create an affordable system of care and support that allows people to get the help they need in a way that maximizes their autonomy and fits with their lifestyle. To accomplish this will require bold steps rather than just incremental ones. We must confront a series of issues:

- How do we create the proper mix of incentives (payment and regulation) to encourage innovation and to create the sort of care people would want?

- What do we do with the extant infrastructure?
- Can we harness the business concept of disruptive innovation, which suggests that cheaper, more convenient products may drive existing ones out of the market, even if the new products are of lower quality (Christensen, 1997)? At first glance, one might decide that no compromise in quality for LTC is acceptable, but how much of our quality standards are arbitrary?
- Will society accept less formally trained care providers who are better supervised through technology?
- How can we offer a positive model of LTC that funders will support?
- How do we create collective responsibility and care coordination?

## Models

The basic components of the proposed change include:

- *Subacute and LTC should be financed and provided separately.* The former should be viewed as a continuation of hospital care and reimbursed under a bundled payment system. The bundle could combine subacute care with hospital care to recognize the inevitable linkage, or it could use a separate point-of-service bundle that would cover all costs after a hospital discharge for a fixed period. Either way, the new model would have accountability for outcomes. The care could be provided in special facilities or at home. Ideally, some more efficient version of rehabilitation will emerge. There is already movement toward creating a more consistent way of paying for subacute care across venues (MedPAC, 2010)
- *No admittance to LTC directly from a hospital.* LTC decisions are complex, fraught with emotion, and need time to explore options. A “cooling off period” would provide an opportunity for more thoughtful decision making guided by counsellors trained to help families to establish goals, reconcile disagreements over goals, and identify service best suited to achieving them. The idea here is that critical decisions should not be made under a strong time pressure. This idea may require some sort of transitional care facility (what used to be step-down units in hospitals.) Obviously we want to avoid too many transitions. Some patients will need intense post-discharge care—their best discharge locations are typically more apparent—but many need primarily observation and recuperation.
- *Payment for all LTS LTC covers only services.* This step would eliminate the distinction between institutional and home and community-based services. Room and board would be covered by a separate payment stream, based on social security and supplemental income sources. All LTC recipients would be entitled to care that responds to their needs, but it could be delivered in various settings that reflected their level of affluence. Clients would live in the setting of their choosing. However, some restrictions on where services were provided would have to apply to encourage efficiency. Various forms of clustered living arrangements, which still allowed client autonomy, would reduce travel time for service providers. Clients would control access to their living space. It is not clear whether social security and supplemental income is sufficient to pay for housing and food that society would consider adequate, but by splitting that coverage away from NHs, we make apparent the underlying policy issue, which faces all poor older people, not just those in NHs. We have granted some misguided exemption to our basic beliefs about people’s right to minimum housing by calling NH life some sort of care situation, where these rules don’t apply.
- *Clients hire/select their own assistants.* LTC organizations would provide some method of oversight from professionals. Clients would be allowed to take informed risks in determining the level and extent of assistance they receive. Obviously, with clients who are severely cognitively impaired some form of agency would be needed.
- *Capitate primary care with payment rates reflecting the outcomes of care.* Fee-for-service payment is an anathema to chronic disease care. Incentives would reward better outcomes such as reduced use of emergency rooms and hospitals and stabilization of clinical trajectories. Primary care providers would be incented to work with LTC providers to create more effective chronic disease management systems. Proactive primary care would move from an appointment-based approach to one that actively tracks patients’ status and intervenes when there is an early indication of change in order to avert a catastrophe.
- *Regulations for both good and bad care.* Such regulations would emphasize (appropriately case-mix adjusted) outcomes and, to a lesser degree, process. Requirements for training would be liberalized to allow for innovative supervisory methods and structured practice. Care would be provided largely by aide level workers supervised through smart phones or other information technology. Some level of clinical supervision by professionals would be needed. This technology could use GPS to check the reliability of aides’ attendance and time spent with a client. It could use clinical tracking forms to oversee aides in monitoring conditions and provide a vehicle for reporting changes in client states that would trigger a more complete assessment. Caregivers would be trained and competent to provide care in a way that

minimizes discomfort and provides the greatest consideration and respect for the individual.

- *Informal care is the backbone of LTC.* Family members should be eligible for assistance—both financial and supportive. They need better tools and training. If we are reluctant to pay them outright, we can use more programs that cash out benefits and allow consumers to pay friends and family for care. Universal coverage of LTC services would be designed as back-ended. Family care could count as the initial care expended to establish eligibility for support. Private insurance could likewise be used to pay for the initial care. A definable risk period would make insurance products to cover the front end more attractive and affordable.

## Barriers

Implementing such changes will be difficult. Perhaps the biggest obstacle is the sunk costs. Large corporations, both for-profit and not, have built (or acquired) many large institutions. Ironically, the LTC business began as a real estate business (Mendelson, 1974). Perhaps it can return to that. Buy-outs may be needed. Incentives for re-orientation will be necessary.

Ironically, some of LTC's biggest advocates for improving LTC may be the strongest opponents to change. A major push-back will come from the people who have spent their lives working to improve LTC. Like World War II veterans, they paid for each inch of beach captured with their blood. They are not prepared to relinquish any toehold on regulations they fought so hard to establish. Somehow they must be won over or worked around. The nature of LTC has changed, as has the theory of regulation. The passage of quality assurance performance improvement (QAPI) legislation reflects this new thinking to some degree. Quality improvement is now at least on a par with quality assurance. Rewards for good care are just around the corner. Some system for rooting out egregious care will always be needed, but it cannot be allowed to dominate.

The caregiving shortage is another barrier. Where will tomorrow's caregivers come from? Both paid and unpaid caregiving needs to be made more attractive. We can never realistically escape the reality that both formal and informal caregiving relies on exploitation. Families sacrifice a great deal to provide care. Wages must be raised, but they will never be high enough to attract hordes of workers. Instead, the work itself needs to be made more rewarding. Most caregivers choose this work as a way to serve, but they need to see that all their effort yields a benefit. Some clients are capable of expressing gratitude for kind and competent care, but many are not. One solution is to create a better information system that shows caregivers how

much difference they make. As with chronic care in general, the only visible outcome is decline. In order to appreciate the benefit of good care one needs a comparator of what the course would be in the absence of such care. Good LTC slows rate of decline; in some areas this slowing may address functioning, in others it may address quality of life, or both; but an effective system should have some measurable benefit (albeit not solely within a medical framework). Thus, an effective information system would contrast the observed path with what would have occurred in the absence of good care (Kane, Priester, & Totten, 2005). This information has to be packaged into simple messages that convey gratitude and provide positive feedback. It needs to be used in creating incentives to reward good care.

Primary care is a key building block of LTC and its erosion poses another serious threat to LTC. This threat extends beyond LTC as well. Effective chronic disease management is central to any effort to improve care outcomes and control costs. Reallocation of resources, improved rewards for better primary care, and new training programs will all be needed. Nurse practitioners can play an important role in increasing the pool of primary care providers (Mundinger et al., 2000; Stanik-Hutt et al., 2013), but they must be enticed into chronic care management along with physicians.

The challenge in urging greater flexibility in care arrangements is how to combine that with more responsibility and accountability. Structures need to be created that hold all three core care elements accountable. LTC is the result of joint production. It will succeed only when all participants (including the client) share a set of common goals, which care form the basis for accountability.

Greater flexibility raises the specter of exploitation. The media regularly features stories of fraud and abuse, but these are a small minority of all care. We need to actively prosecute the scallywags, but vigilance in detecting them cannot stand in the way of building a system that allows more individualized values and creative ways to deliver desired care.

## Conclusion

The ultimate challenge is how to create an appetite for change. LTC currently carries a strong negative image. We need to create a public dialog about LTC that will make it a political issue. When politicians campaign on a platform of improving LTC, we will have achieved a milestone. To convince people at all levels that improving LTC is both feasible and worthwhile we need to start by changing the vocabulary we use to describe LTC. If you ask people what they want from such care, they use words like "choice," "autonomy," "dignity," "respect," and "control." They

want to be able to take informed risks. Public discourse should focus on how to achieve these ends. There is reason for optimism. In the face of changing demographic and economic realities, our society has made great social strides in the past decades. The major social movements of our times—the women’s movement, civil rights, and gay marriage have come about when social forces argued that the current situation was unjust. So it is with LTC.

We cannot continue down the current LTC path. Alas, we cannot take both forks. We need to start planning actively for a new form of LTC that addresses the primary goals of such a service and is affordable. Making large scale change will inevitably generate opposition. A lot of people and organizations have heavy investments in the status quo. Re-inventing LTC will involve giving up some cherished beliefs. The first step is to free ourselves of ideas we have internalized over the years and start with as clean an intellectual slate as possible. Get back to basics. What are the primary goals of LTC? What are its core elements? How might they be repackaged to achieve desired social ends? I believe the goal is allowing people to age with dignity and choice. The three building blocks of LTC are housing, personal care, and health care. Everything else about LTC is on the table.

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